

**Introduction to Rehabilitation Ethics & Ethics in Long-Term Home
Care;**
Disability Rights, Disability Studies

Mark Kuczewski, PhD
<http://bioethics.lumc.edu>

Objectives:

At the end of this session, participants should be able to:

- (1) Identify differences between ethical issues in rehabilitation care and the acute care hospital
- (2) Identify differences between ethical issues in long-term care and the acute care hospital
- (3) Develop a framework for dealing with ethical concerns in rehabilitation and long-term care
- (4) Apply this framework for dealing with ethical concerns in rehabilitation and long-term care to difficult cases.
- (5) Identify what is often called “the disability perspective” on bioethical issues.
- (6) Analyze the disability rights movement as an analog or kind of civil rights movement
- (7) Identify the importance of concepts such as “universal access”

Readings:

Arthur L. Caplan, Daniel Callahan, Janet Haas, "Ethical and Policy Issues in Rehabilitation Medicine," *Hastings Center Report* Special Supplement, 17: S1-S19, August 1987.

Charles W. Lidz, Robert M. Arnold, “Rethinking Autonomy in Long Term Care,” *University of Miami Law Review*, 47(3): 603-623, 1993.

View Video: Rehabilitation Institute of Chicago, Women with Disabilities Speak to Health Professionals, “Access” (On your CD-ROM)

Mark G. Kuczewski, Rosa Lynn Pinkus, *An Ethics Casebook for Hospitals*, Case 2 (pp. 8-13), Case 20 (pp. 117-121), Case 24 (pp.143-147), Case 25 (pp. 148-155)

Rosalie Kane, Arthur Caplan, *Everyday Ethics: Resolving Dilemmas in Nursing Home Life*, New York: Springer Publishing Company, 1990, pp. 71-89, 125-136.

Mark G. Kuczewski, "Disability: An Agenda for Bioethics," *American Journal of Bioethics*, 1(3): 36-44, 2001.

Also, visit these important sites:

<http://www.notdeadyet.org/>

<http://www.ragged-edge-mag.com/>

<http://www.nod.org/>

<http://www.disabilityworld.org/>

<http://www.adapt.org/>

<http://www.mouthmag.com/>

Suggested Further Reading:

Susan Dodds, "Exercising Restraint: Autonomy, Welfare, and Elderly Patients," in Matt Weinberg, *Medical Ethics: Applying Theories and Principles to the Patient Encounter*, Prometheus Books, New York, 2001, pp. 73-79.

Deborah Raines, "Ethical Implications of Genetic Testing," in Matt Weinberg, *Medical Ethics: Applying Theories and Principles to the Patient Encounter*, Prometheus Books, New York, 2001, pp. 494-506.

The Americans With Disabilities Act,

<http://www.dol.gov/dol/topic/disability/ada.htm>

(I) Introduction – Informed Consent Beyond the Acute Care Setting

Medical Ethics has squarely embraced **respect for patient autonomy** as its **favored principle** and its corresponding **framework, informed consent**, as its mode of **implementation**. Of course, medical ethics developed mainly in the **acute care** hospital. As a result, there are questions concerning how one can apply the principle of respect for autonomy and the doctrine of informed consent in other settings. We will consider two settings in particular: the **rehabilitation facility** and the **long-term care setting** (nursing home).

The **typical image** of informed consent is based on a picture such as **surgery**. The physician gives the patient facts about the risks and benefits of treatments and makes a recommendation. The patient ingests the information, sees how they fit with his values, and then issues a preference for one treatment or no treatment. The articles on rehabilitation care and long-term care make clear that this model is not widely usable in rehab or nursing homes. But, in an effort to build upon and develop the language of autonomy and informed

consent, rehab and long-term care **reinterpret** and **extend** the notion of informed in new directions.

Even within acute care, the alternative model of informed consent, the **process model** has been recognized. The process model sees informing as an **experiential** process that takes place in a variety of ways over time and autonomy as more of an outcome than a precondition, is the **dominant** approach in **rehabilitation**. Because the patient becomes more knowledgeable regarding the options and his or her preferences, this is called the **educational model** in the article by Caplan, Callahan, & Hass.

In **long-term care**, informed consent seems hardly applicable as a way to implement autonomy. **Decisions** are **not** so **discrete** and identifiable. The patient is not autonomous in the typical ways of being able to choose freely and uncoerced or to deliberate effectively. **Autonomy** must be reinterpreted as creating a **life-style** or **way of being** that is consistent with how the patient has lived his or her life.

In **acute care**, the emphasis is always on the **patient** as an autonomous agent who **manipulates** the **environment** through choices. In settings such as **rehabilitation** and **long-term care**, the ability of the patient/client/resident to manipulate the environment is extremely limited. Bioethics calls attention to the need for **providers** to foster autonomy through **affecting** the **environment** on behalf of the patient.

(II) Two Models of Informed Consent: Event v. Process

We have spent a good deal of time this semester talking about the two main models of informed consent: informed consent as an event and informed consent as a process. Insofar as informed consent has any widely generalizable value in the rehabilitation and long-term care setting, it is in terms of the process model. It is worth reviewing the qualities informed consent must have in order to be applicable outside of acute care. By doing so, we will also see that we have stretched informed consent to the limits of its structural integrity. As a result, some argue that we should abandon such language in favor of an alternative language such as an ethic of care.

Event Model v. Process Model
Legalistic v. Contextual
Contractual v. Educational
Informational v. Experiential
Autonomy v. Narrative Integrity
Choice v. Consistency

An event model of informed consent is legalistic in that it is mainly concerned with giving information to a patient and obtaining the patient's permission for a procedure. The original purpose of this is often thought to have been for the patient to waive the provider's liability for possible negative outcomes of the procedure. In this way, it is something like a contract. Furthermore, the informed consent event instances an exchange of information that is cognitive in nature, e.g., risks, benefits, etc. Insofar as there is an ethical ideal behind an event model of informed consent, it is that of a patient making an autonomous choice based on the combination of information and his or her values.

As we have already noted, much of the day-to-day care in environments such as rehabilitation care and nursing home care do not lend themselves to this model of information giving and choice. How patients or residents respond to their care is something that can only be determined over time as they gain experience with their limitations, possibilities, and surroundings. In such a setting, the person's decision-making capacity seldom is a matter of rational choice. Rather, their capacity is measured in terms of consistency with their values and lifestyle. As a result, the value that is respected is the narrative integrity of the person's life rather than his or her autonomy. At this point, we can see that informed consent borders on being simply a metaphor or analogy. Informed consent is so closely tied to notions of autonomy and choice that when the goal of the caregivers becomes fostering the narrative integrity of the patient/resident, we can claim that this is no longer informed consent. Instead, we have the caregivers being guided by appropriately paternalistic motivations such as beneficence and care. As we analyze cases, we must consider if it is valuable to retain the language of informed consent is worthwhile or we would do better to expand our ethical vocabulary.

(III) Ethics in Rehabilitation Care

Rehabilitation is generally seen as having **three** distinct **ethical features**:

- (1) An environment that requires **informed consent** be interpreted along the lines of an **educational** or **process model**
- (2) A **team approach** to care
- (3) An approach to care that demands an intimate role for the **family**.

Rehabilitation must be conceived as a **process** for a number of reasons. Patients have often suffered a devastating **change** in **future prospects**. They may not immediately grasp their situation or what kind of life is **possible**. Lifelong plans may be dashed, values need to be re-evaluated, etc. The patient probably cannot make **truly competent** choices initially because of an inability to appreciate all of these factors. The patient must be educated regarding the possibilities.

The patient participates in therapy with a variety of members of a **health-care team**. The team usually meets at fixed intervals to **evaluate progress** toward **goals** and to **re-evaluate** the **goals**. Because of this structure, there is a danger that **patients do not know** how they are being **evaluated** *and never gain a toehold into the consent process* (they do not perceive a point of entry into the conversation). As Caplan, et al. note, **discharge** can come as a **surprise** when the patient/family are not adequately kept in the loop. This problem is heightened all the more by the **subjective nature** of **progress** in rehabilitation.

The **family** is usually an intimate part of the therapy process for several reasons. Most obviously, families are likely to assume a **future care giving role**. They are often being **educated** by the therapists into their future role. If the family is unwilling to undertake such a role, or if there is no family, this **directly affects** what **goals** are achievable. As a result, a patient is a better "candidate" for rehab if he or she has a supportive family unit.

Other distinctive ethical features of rehabilitation care:

Commitment to **prevention** -- many injuries are preventable with precautions, e.g., falls, head injuries, etc. Rehabilitation facilities often demonstrate a commitment to community education regarding prevention.

Political -- Rehabilitation facilities often show a commitment to community activism regarding disabled persons.

Volunteerist environment -- rehabilitation facilities tend to have huge volunteer staffs. The ethical import of this is not clear but does show a relationship to the community that is not paralleled in many sectors of the health-care system.

(IV) Case Illustration

(Please be sure to read Mark G. Kuczewski, Rosa Lynn Pinkus, [*An Ethics Casebook for Hospitals*](#), Washington, DC: Georgetown University Press, Case 24 (pp.143-147) **before proceeding further.**)

The case of Mr. X demonstrates many of the salient features of ethics in rehabilitation care. In this particular case, we seem to have a patient who possesses decision-making capacity. And, he seems to consent to the goals of treatment at moments but balks when it comes time for the actual treatment. This kind of temporal separation between consent to goals and consent to treatments is characteristic of a process model of informed consent. This is only natural because Mr. X is being treated in rehabilitation for a long-term chronic illness and we recall that process models work better in situations of chronic illness.

Perhaps more interesting is the way in which others affect the consent process. Initially, the main question confronting the health-care providers was whether they were entitled to be somewhat “persuasive” (perhaps “coercive”) in getting Mr. X to therapy in the mornings. Clearly, it seems appropriate to try to influence Mr. X to do what is best for his health, i.e., participate in therapy. But just how far are they allowed to go? Part of that answer seems to be in terms of the potential outcome of therapy. If Mr. X’s living situation were likely to change little even with therapy, then we might wonder what purpose was being served by cajoling him into participating. Such paternalistic interventions would quickly be seen as unjustified. But, Mr. X’s son will allow his father to live with him if Mr. X met certain rehab goals. Because this goal seems worthwhile and Mr. X is somewhat interested in attaining it, persistence in trying to get him to daily therapy seems more justifiable. Thus, where we draw the line between influence and coercion is somewhat dependent on familial and environmental factors.

We can also see that this case looks different from many we have examined in terms of the person facing the dilemma. In the case of Mr. X, the problem confronts the physical therapists who must treat Mr. X every morning. These professionals represent an additional layer of caregivers who are part of the rehabilitation team. They are caught up in a dilemma of informed consent. In the acute care setting, informed consent is seen as the province of the attending physician. But in rehabilitation, the process of informed consent, a process that spans so much time will necessarily come to involve all of the team members. And these team members must work together in trying to resolve the issue.

The main danger that confronts a team approach to care giving is that the closeness of the team, its main strength, actually becomes its weakness. This can happen through “group think” in which the team members reinforce each others’ opinions and leave no room for doubt regarding their conclusions. In the case of JP, this threatened to happen when the rehab team began to see the mother as another patient “in denial.” This woman’s assertions concerning the hope she received at her support group was simply dismissed out of hand. Fortunately, this team managed to negotiate compromises with her including backing off her judgment on the feeding issue.

In these cases, we saw that the doctrine of informed consent and the usual theory of surrogate decision making were still applicable. Treatment goals could be negotiated, set, and renegotiated. Treatments and therapies could be selected in accord with these goals. The values of the patients and families were relatively stable and were translated into treatment preferences through a process. Some rehabilitation cases (e.g., severe spinal cord injuries or profoundly challenge the applicability of the informed consent model. This is because the nature of the injury is so all encompassing that the person’s previously held values may no longer be relevant to the choices before him or

her. As a result, issues of **personal identity** must be tackled. (We'll wade into this in the **Disability & Bioethics** section further on)

(V) Ethics in Long-Term Care

The article by Chuck **Lidz** and Bob **Arnold** (1993) points out that autonomy has several possible meanings. Most of them assume the informed consent framework, e.g., autonomy as free action, as effective deliberation, etc. Lidz and Arnold point out that these conceptions of autonomy are simply not applicable to most of what happens in long-term care. In particular, any view of autonomy that assumes discrete choices to be made will be lacking. Lidz and Arnold point to a conception of **autonomy as consistency** as the meaning it must assume in this context.

Consistency must be **interpreted** within the framework of a **narrative conception** of human life. On the one hand, consistency simply means *making decisions the way the person has always made them*. But, as Lidz and Arnold note, we cannot simply always base decisions on who the patient was. The patient also has a **present** and **future** that must be considered. Consistency means a kind of **relative continuity** and **stability**, a **way of being**. As a result, what is required is the **preservation** of the **identity** of the resident as far as possible and decisions that have the kind of continuity that is appropriate to **life "stories."**

It is important to be clear that one of the reasons long-term care differs from other settings is that the persons involved are **not patients**. They live there and are **residents**. As a result, the **standard justification** for certain **violations** of **autonomy**, i.e., that they are needed to restore the patient to their baseline state, is often **inapplicable**. The state of residents in the nursing home is often their baseline state.

This feature of being residents also means that many of the problems encountered will be problems of **living, not death**. Claims on the resources of the facility, on the responsibilities of family and other residents to a particular resident will often be at issue. Much of how we assess the moral content of solutions to these matters will hinge on what kind of community we believe a long-term care facility to be, e.g., more like a hotel, a neighborhood, or a family.

Typical Problems in Long-Term Care:

Routine -- How much is an institution justified in imposing rigidity in the schedule of

eating, sleeping, bathing etc.?

Wandering & the use of restraints

Hitting of one resident by another

Room assignments
Patient transfer
Feeding tube issues

Additional Case Illustrations

(Please be sure to read Rosalie Kane, Arthur Caplan, *Everyday Ethics: Resolving Dilemmas in Nursing Home Life*, New York: Springer Publishing Company, 1990, pp. 71-89, 125-136 and Mark G. Kuczewski, Rosa Lynn Pinkus, [*An Ethics Casebook for Hospitals*](#), Case 2 (pp. 8-13) **before proceeding further.**)

These cases illustrate the importance of the principles of respect for autonomy and beneficence in dealing with the disabled and the elderly. However, they will also show us that we may need **additional principles** such as **family responsibility**, **candor**, and **responsibility for narrative integrity** in order to deal with these hard cases. Furthermore, the relationship of the patient or resident to the **community** will be at issue.

The case of “**The Chair**” creates questions of the responsibility of **one resident** of a nursing home **to another** and of the **institution to each resident**. How one analyses this case depends to some extent on **what kind of community** you believe the nursing home to be. Nursing home staff often see it as an intimate community most akin to a home and family. As a result, such professionals often argue for Mrs. Crotchet’s right of way concerning the chair. They sometimes also suggest that Mrs. Crotchet or her family purchase this chair or another like it so her claim to it has a basis in our normal intuitions about property. In contrast, if we see nursing homes as **impersonal communities** that are not genuine living spaces, e.g., a **hotel** or acute care **hospital**, then we tend to analyze this case in terms of rights and the impartial treatment of all. As a result, we would then think the staff should enforce the claims of Miss Newly.

In “**Phone Privileges**,” we see some different issues being raised. The boundaries of the institution are fluid and the problems of a family and the staff cannot be extricated. The **staff** can only resolve their problem by forcing the **family** to face theirs. This case is presented from the point of view of the caregivers and they are clearly in danger of succumbing to the temptation to see this as an issue only for Mrs. Allison's family. Because it is the family that was initially less than candid with Mrs. Allison about her length of stay at the nursing home, it would be easy to see the moral issue as simply a matter of “family responsibility.” And this case, indeed, requires that the family take some responsibility for being candid with Mrs. Allison. As Laurence McCullough astutely notes about this case, it is unlikely to be resolved unless the family members are willing to engage in a process of dealing with the

problem. But McCullough notes that this case is a “problem” mainly for the nursing home staff, not the family. That is, it is the nursing home staff that are asking themselves what they should do. As a result, the resolution of the case will probably be accomplished by the staff facilitating discussion between the family and the resident. But, by what principles do they do this? McCullough suggests a framework for geriatric care that employs the three principles of **(1) respect for autonomy, (2) beneficence, and (3) family responsibility**. We could certainly give an account of this case in these terms.

We can easily imagine an argument that the resident is entitled to the truth because it respects her autonomy, may relieve her mental anguish (beneficence), and that it is the family's responsibility to join in the process of relieving her suffering (family responsibility). But this is an indirect analysis and one that requires we go a long way to interpret the principles. One could just as easily argue that the principle of respect for autonomy is inapplicable (i.e., her mental faculties are diminished and there is no real choice for her to make) and that not forcing the ultimate truth from her about the length of her placement is an attempt to be beneficent.

McCullough advocates that the nursing home staff gather the family to facilitate discussions that ultimately resolve the information issue and to find ways to address Mrs. Allison's needs. This is clearly the correct solution. But this solution calls to mind **concepts** that are **more obvious** than the three he employs. For instance, it seems clear that caregivers (and families) have a certain duty to be candid with conscious patients. This has little to do with any choice to be made but makes apparent that it is simply right to be forthright. Many good effects generally follow---the patient is less anxious, the staff are relieved of the burden of orchestrating deception, the family functions better, etc. But it is not any one of these effects that makes candor a duty. It is a duty for all of these possible reasons and for still more.

Furthermore, the **duty of candor** is simply more direct in calling forth the appropriate particular actions in this kind of case. Respect for autonomy brings to mind choice but requires some inferential reasoning to suggest truthfulness. If Mrs. Allison's family had been told that they must clear up this misunderstanding because the nursing home recognizes the duty to respect autonomy, the family might not have been sure what the implications of this concept are for their particular situation. But, had the family been told that the nursing home explicitly requires candor of its staff in dealing with all conscious patients, the family members would know that the caregivers would clear up the misinformation regarding the permanence of the placement if they would not.

Much of the function of principles in bioethics is service as **maxims** or **rules of thumb** that can guide action. Persons of experience such as these nursing home staff have become proficient at recognizing the appropriate action.

Then, they are able to distill a rule of thumb that generally guides action and use such a rule to educate new colleagues and residents and families who are tackling these issues for the first time. In the preference for candor over respect for autonomy as a rule of thumb in this situation, we see that **moral experience** tends to **elucidate the principle**, not vice versa. But such concepts, once distilled, can be of aid in the gray areas of experience (This is *casuistry*, right?). Candor can clearly serve as such a guide in those many troubling instances when families approach a caregiver and ask that less than the full truth be given to their loved one.

The most obvious points for discussion in **Case Two** of the Kuczewski & Pinkus casebook concern the many missteps of the neurosurgeon. He appears to have been well-intentioned but faulty in his instincts. On the positive side, he was concerned to find an appropriate surrogate decision maker for Mrs. F. However, he seems to have presumed from the outset that she could not speak for herself and to provide consent for treatment. Furthermore, he demonstrates something of an age-ist bias. That is, because Mrs. F was elderly, he presumed that aggressive treatment was not appropriate despite her previously high quality of life and the clear medical indications for the procedure. Of course, the information regarding her quality of life seems not to have been available to the neurosurgeon.

It is likely that the information about Mrs. F's level of functioning was provided to the narrator of the case by the staff of the nursing home. Mrs. F's nephew was rather removed from knowledge of her personal wishes and functional status and there are no other significant relationships mentioned. But this information about Mrs. F's baseline status was not conveyed adequately to the neurosurgeon and he was not inclined to turn to the nursing home staff to seek it. As a result, such information would have required a proactive intervention from the nursing home staff in order to have been relevant in the decision-making process.

Much of the problem in this kind of case probably stems from *artificial barriers erected by custom, law, and state regulation*. Customarily, health-care providers turn to the next of kin for guidance in making decisions for an incapacitated patient. Similarly, state laws sometimes codify an order to the persons who should serve as surrogates, e.g., guardian, spouse, adult child, parent, etc. Some states even go so far in their suspicion of caregivers as to restrict whether and which personnel of the institution may serve as witnesses to important documents such as advance directives. Clearly, the intent of these habits and laws is sound. They are advanced in an effort to allow those who know the patient/resident best to determine what she would want or what is in her best interest. However, when the people who know what she would want or is in her best interest are employees of the long-term care facility, this approach is counter-productive.

In our society, cases similar to Mrs. F's will become more frequent. As families become less extended in nature and persons outlive their close relatives, the immediate **community** surrounding the resident is likely to become the **repository of** what is known about **the patient's functional status, values, and likely preferences**. The immediate community will be the ones who best know "**who the resident is**" and will be in the best position to say what choice will best make the future of this person in accord with who they have always been. In other words, those who live near the resident, either friends, acquaintances, or nursing home staff are more likely to be the best qualified to exercise the normal health-care decision-making functions. If we are truly intent on quality decision making for the elderly, this role must become more widely accepted and long-term care institutions must accept their responsibility for preserving the **integrity of the patient's life-story**.

I am not arguing that long-term care facilities should become the surrogate decision makers of choice for the elderly. I am asserting that these caregivers probably have a responsibility to monitor the decision-making process for their residents and to be sure that the process upholds the integrity of the person, the integrity of who that person is and what her life means. It is not a matter of seeing only one meaning or theme to a person's life. In focusing on **narrative**, the concept calls us to see the **person's story** and to help determine **what should come next**. That is, the long-term caregivers must see to it that the decisions made for the incapacitated resident are consistent with the life and decision-making style of their resident. Decisions for the patient should be made in a way that is similar to the way patients always made decisions. In the case of Mrs. F, this means taking responsibility to see how the process was proceeding and to be supplying all the social information the nursing home staff possess. It does not matter much whether the ultimate locus of the decision is Mrs. F's nephew, the neurosurgeon, or someone from the nursing home. What matters is that the decision be made with the full knowledge of Mrs. F's way of being that the nursing home staff possessed and in a manner consistent with that information.

This **principle of responsibility for narrative integrity** is similar to the idea that respect for autonomy means **facilitating autonomy**. In a case like Mrs. F's, one can argue that the nursing home personnel have a duty to supply the information they know so that a decision can be made consistent with Mrs. F's values. Respect for autonomy implies not only acting on the known preferences of an incapacitated patient but also appreciating the lifestyle and values of the person and being sure that any choices constructed on his or her behalf are based on these givens. Of course, this is a subtle meaning of respect for autonomy and not the one in common parlance. To the nursing home staff, respect for patient autonomy only suggested that they send Mrs. F's medical records and the name of her next of kin. It did not suggest they had a direct responsibility to be a part of the decision-making process, a vital role as the keepers of her narrative history. Because people tend to believe they know

what autonomy means, the concept of respect for autonomy is unable to suggest its implications for this kind of case. The term's focal meaning is so well known that it is unable to call forth its important secondary meanings. As a result, a new term is likely to serve this purpose better.

Disability & Bioethics

History (of sorts)

- (1) Rehabilitation ethics – 1987 HCR article
- (2) Medical versus social model of health care – the independent living movement
- (3) Disability, discrimination & alternative culture
- (4) Civil Rights and Justice for All: The Americans with Disabilities Act (ADA) (1990)

Definition of Disability ([American's with Disabilities Act \[ADA\]](#))

“A physical or mental impairment that substantially limits a major life activity such as walking, seeing, hearing, learning, breathing, caring for oneself or working.”

It protects “Those who have a disability, those who have a record of such impairment” (e.g., cancer survivors) And those who “are regarded as having such an impairment” (e.g., disfigurement)

Most frequent health conditions leading to disability:

- Back problems
- Heart disease
- Arthritis
- Asthma
- Leg or foot problems
- Psychiatric disorders
- Learning disabilities
- Diabetes
- Cancer
- Cerebral vascular disease

Some Rehabilitation Ethics “Classics” (See also the [Resources in Disability and Bioethics](#) page of the Neiswanger Institute)

Arthur L. Caplan, Daniel Callahan, Janet Haas, 1987. "Ethical and Policy Issues in Rehabilitation Medicine" Hastings Center Report Special Supplement, 17: S1-S19.

Hilde Lindemann Nelson, James Lindemann Nelson, 1995. *The Patient In The Family: An Ethics of Medicine and Families*, New York: Routledge.

Ruth B. Purtilo, 1988. "Ethical Issues in Teamwork: The Context of Rehabilitation." *Archives of Physical Medicine and Rehabilitation* 69(5): 318-322.

Janet Haas, 1993. "Ethical Considerations of Goal Setting for Patient Care in Rehabilitation Medicine." *American Journal of Physical Medicine and Rehabilitation* 72(4): 228-232.

Kenneth Gerhart, Jane Koziol-McLain, Steven Lowenstein, Gale Whiteneck, 1994. "Quality of Life Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers," *Annals of Emergency Medicine*, 23(4): 807-812.

Ruth B. Purtilo, 1984. "Applying the Principles of Informed Consent to Patient Care: Legal and Ethical Considerations for Physical Therapy." *Physical Therapy* 64: 934-937.

Karen Grandstand Gervais, Dorothy E. Vawter, and Emily Spilseth, 1995. "Readings in Rehabilitation Ethics." *HEC Forum* 7(2): 183-197.

Some Disabilities Studies Works:

Lennard J. Davis, *My Sense of Silence: Memoirs of a Childhood with Deafness*, Urbana-Champaign: University of Illinois Press, 2000

Gelya Frank, *Venus on Wheels: Two Decades of Dialogue on Disability, Biography, and Being Female in America*, University of California Press, 2000

Albert B. Robillard, *Meaning of a Disability: The Lived Experience of Paralysis*, Philadelphia: Temple University Press, April 1999.

Claudia L. Osborn, 1998, *Over My Head: A Doctor's Own Story of Head Injury from the Inside Looking Out*, Kansas City: Andrews McMeel Publishing.

Robert McCrum, 1999, *My Year Off: Recovering Life After a Stroke*, New York: Broadway Books.

Doris Zames Fleischer, Freida Zames, 2001, *The Disability Rights Movement: From Charity to Confrontation*, Philadelphia: Temple University Press.

Christopher Reeve, 1998, *Still Me*, New York: Ballantine Publishing Group.

Michael Oliver, 1996, *Understanding Disability: From Theory to Practice*, New York: St. Martins Press.

Rehabilitation and the Problem of Patient “Autonomy”

As we have seen over and over, the cornerstone of all clinical bioethics is the doctrine of informed consent. Informed consent is originally a legal doctrine based on a set of philosophical premises. The legal doctrine can be characterized as requiring that any touching of a person (patient) must be authorized by that person. For this authorization or permission (consent) to be valid, it must follow the disclosure of the risks and benefits of the proposed procedure. In other words, the person must be informed about what it is he or she is consenting to.

Informed consent is sometimes said to involve the elements of disclosure, understanding, and choice. That is, the physician must tell the patient what she proposes to do, the benefits and risks of the proposed treatment, and about alternatives to the proposal including doing nothing. The patient needs to cognize these facts in some fashion, and then to make a choice to grant permission to or with hold consent from the proposed treatment. The patient takes in the facts, evaluates them in light of his or her values. Choice is, ideally, the bringing together of these facts and values.

Of course, the patient must be “competent” to make the decision. That is, he or she must have the capacity to take in the information and make a choice. Decision-making capacity includes the ability to cognize information and to interpret this information in terms of one’s values. Decision-making capacity will generally be an entity that one “more or less” possesses rather

than an “all or none” kind of thing. For instance, the cognizing of information is subject to wide variation. We cannot require that patients understand and analyze the information in the way physicians and health care professionals do. Something less must do. But, exactly where an acceptable layperson’s understanding of the information passes into an inability to grasp the relevant features of the proposed treatment is simply not clear and must be evaluated on a case-by-case basis. Similarly, determining when a patient is making decisions according their values in a way that is characteristic of their decision-making style is not always obvious to health-care professionals and can require the assistance of persons who know the patient well, such as family members.

The model of informed consent we have been describing evolved within the acute care context, so it should be no surprise that it works best for an acute illness. For instance, imagine a patient with a new diagnosis of breast cancer. The physician can explain a variety of options such as radical mastectomy, lumpectomy, either of those surgical options followed by chemotherapy, and no treatment at all. The choice of treatment options will clearly involve the values of the patient and how much weight the particular patient places on the side effects of each treatment versus the relative efficacy of each option. As complex as informed consent is in this kind of situation, a traumatic injury or disability complicates this schema exponentially.

The difficulties related to the informed consent procedure relate both to patients who are conscious and would normally be considered competent as well as to patients who are unconscious and unable to express their wishes contemporaneously. In both cases, the philosophical difficulty relates to the relevance of the values developed as an able-bodied person to the person with a disability. This can be easily illustrated.

When a person suffers a trauma that results, for instance, in a brain injury, spinal cord injury, blindness, or disfigurement, their life prospects can be greatly changed. Many of the things the person did routinely may be no longer available to him or may have to be done in a very different manner. It

may well be difficult for the patient to appreciate what the possibilities for his future are. From the vantage point of the life plan, goals, and values the person had developed over the years, his post-trauma prospects may seem nothing more than indignity, drudgery, and misery.

In the acute illness situation, the question for the patient usually concerns what he is willing to undergo in order to try to get back to his pre-morbid condition. When an injury results in a major physical impairment, there is no possibility of return to the pre-injury status. Thus, the issue of informed consent concerns what treatments the patient is willing to undergo and in what rehabilitation efforts he is willing to participate in order to achieve physical stability and enhance his ability to perform activities of daily living and, perhaps, attain a satisfying level of community integration. Two problems follow from this schema.

First, it is difficult for any patient to prospectively evaluate how beneficial or burdensome treatments and care plans will seem until he or she has partaken of them. It is difficult to know what being ventilator-dependent is like until one has been on a ventilator and a person who is orally intubated may not appreciate the relative freedom that would come with having the ventilator attached via a tracheotomy tube. *Second, there is a philosophical problem in simply applying the values of an able-bodied person to one who has a significant disability.* Persons who do not have impairments routinely rate the quality of life of a person with a disability lower than the person who has the disabilities. During the immediate post-trauma phase of care, a patient essentially has the values of their pre-injury condition and has not yet experienced the possibilities for living with a disability. In the last lecture, we saw that prominent ethicists such as Art Caplan & Dan Callahan have argued that informed consent must proceed according to an “educational model” or “process model” in rehabilitation care.

An **educational model of informed consent** stresses that a patient needs an opportunity to **experience** the **post-traumatic phase** of care. In essence, the argument is that the treatment team may be more paternalistic

during the initial phase because the patient is not yet fully informed as becoming informed is an experiential process. Therefore, in the initial stages, the patient cannot give informed consent. As the patient experiences life with a disability, he or she essentially becomes more “competent” to make decisions regarding care, care that may determine whether the patient lives or dies. Others have pointed out that this process can take a very long time and would constitute a denial of a patient’s right to self-determination. As our values comprise what we usually think of as the core of our character, it is not surprising that forming new ones may take up to five years. One could not reasonably deny a patient his or her right to refuse treatment for such a length of time. Nevertheless, it is reasonable to be cautious in assessing the patient’s decision-making capacity in the immediate post-traumatic phase of care. Being sure that emotional disorders such as depression are treated and waiting for certain conditions that might affect the person’s mental status, e.g., swelling of the spinal cord, to subside before honoring refusals of life-sustaining treatment are counseled by the traditional frameworks for assessing decision-making capacity.

Acquired Disability and Informed Consent: The Incompetent Patient

Similar problems occur if the patient is unable to speak for him- or herself and important decisions must be made regarding potentially life-sustaining treatment. As the patient’s wishes regarding such treatment is the gold standard for decision making, we first seek any directions the patient may have given in advance of the current medical crises. If the patient's directions are clear, they must be followed. But “advance directives” are not available in most instances. Even when such documents exist, they are seldom specific enough to be directly applied to the treatment issues at hand.

When no advance directive is present or the patient’s wishes need to be interpreted, a surrogate, usually a family member, must help make

decisions for the patient. The traditional approach to surrogate decision making is called “substituted judgment.” This approach to decision making asks the surrogate to make the decision the patient would make for him- or herself when competent.

Substituted judgment is sometimes a simple matter. Most patients want potentially beneficial treatments and it is a simple matter consent on behalf of a patient to clearly effective interventions. However, when it is not so clear that a treatment will be efficacious or the treatment can be considered burdensome, determining what the patient would have wanted is a less precise exercise. Nevertheless, attempts to study how well surrogates can guess what patients would want suggest that they are reasonably good at it. Substituted judgment faces the same conceptual difficulties as does informed consent. While the patient or a surrogate can apply the values of the pre-injury patient to the current treatment choices, the question of the relevance of those values to the patient’s current interests is very pressing. The patient’s values may have been developed in a very different context and it may be seemingly contrary to the best interests of the patient to apply those values. This is sometimes cast in the metaphor of becoming a “**different person.**”

Exactly what makes one a “person” and what defines one as the “**same**” **person** through time have been matters of scholarly controversy. The attempt to define or describe “personhood” is an effort to explain what separates human beings from other forms of life (i.e., plants and other animals) and thereby gives humans greater moral status. Presumably, once a human being has lost all the characteristics that accompany personhood, different ethical principles might govern medical decision making. For instance, a body that has lost all personhood (e.g., a corpse would be the clearest example) might be entitled to a kind of respect but would command no obligation to beneficence, e.g., as in medical treatment. However, we need not definitively answer the question of what makes one a person to at all to appreciate the issue of what makes one the same person.

The most common answer to the question of **sameness of personhood** usually involves **psychic continuity**. That is, we are the same person because we think and act as if we are the self-same person through time. Although consciousness of self is usually involved, it need not be. That is, one can imagine persons whose personal style and habits persist even when self-consciousness wanes. Two implications follow on this view. First, to the degree that a decisionally incapacitated patient still exhibits psychic continuity with his pre-morbid state, his prior values should be applied to the current situation by the surrogate decision maker. Second, it is possible to become a different person to whom one's previous values do not apply. When psychic continuity is minimal or non-existent, one may argue that the previous values (and directives) are no longer applicable. Just as competent patient may not be able to appreciate the altered life prospects that come with his new disability, the surrogate may undervalue the life prospects of the patient if he or she is restricted to applying the "former" person's values to the "**new**" person.

The language and metaphysics of "new" persons make certain points salient but are unlikely to be entirely persuasive, especially in the **clinical context**. They capture the intuition that normal approach of acute care medicine to surrogate decision making is too rigid in applying the values of the pre-injury patient. Somehow, the present-oriented interests of the patient would seem to have to count for something as well. However, it also seems unsatisfactory to suggest the opposite, i.e., that those prior values should count for nothing once a patient's interests have changed dramatically. As a result, more communitarian interpretations of substituted judgment have received much attention in recent years.

Communitarian commentators argue that the problem with scholarship on medical decision making is that it generally relies on a very static view of the person. The person is often conceived as an individual with a fixed and abiding set of values that can be applied to treatment decisions. Of course, this quite often fails to reflect the reality of medical decision making. Persons often do not know what their values are regarding specific medical

situations with which they are unfamiliar. Or, they may have reasonably well-developed values, e.g., dislike of pain, but have no idea how this should figure in particular treatment decisions.

What so often happens in medical decision making is that it takes the form of a dialogue between the patient and significant others. The patient comes to know his or her own mind through this dialogue in which he tests his thoughts by the light of the feedback of the other. In this way, the patient's values take shape or find an appropriate application to the treatment choices at issue. For instance, consider a simple question non-medical decision such as what kind of car to buy. What kind a person "wants" is not just what he wishes for in his daydreams. It might well be the outcome of a process of consultation between the person and his or her significant other. To some extent, the person does not really "know" what he wants until he goes through this communal deliberative process.

If informed consent is this kind of communal process, then surrogate decision making should be conceived similarly. When asking a surrogate to make a decision as the patient would, we should not be asking what the patient would have said about this state before he was in it. We are really asking the person to "continue" the process of the development of values or their interpretive application to the treatment choices. That is, imagine the deliberative process the patient would go through in concert with his or her significant other and where that outcome might end. Just as with the competent patient, such a deliberative process might end in a choice that failed to properly value the life possibilities available to the patient. But, it might also end in a recognition that the person might adapt to the new possibilities of this life. Such a decision-making process would more closely mirror the way clinical decision making proceeds. That is, clinical decision making is often a fairly collaborative and intuitive process. It seldom mirrors the legalistic terms in which it is so often discussed.

In many ways, the **problem of personal identity** is not so much a philosophical problem as it is a question of **how to facilitate the informed**

consent process. Despite the difficulty in truly appreciating the future prospects for life with an impairment, the clinician must facilitate such appreciation to the greatest extent possible. Specific approaches to this problem are not easy to come by. But such a process likely involves coming to identify oneself in new ways.

In sum, two points are worth noting. *First, clinicians who treat persons with disabilities immediately after a traumatic injury face a great challenge to the informed consent process in helping the patient or his surrogate decision maker to appreciate the possibilities for his or her future with an impairment.* This problem is the same in structure whether we are dealing with a competent patient or his or her surrogate decision maker. As a result, in all cases, one has to proceed in a way that takes the patient's prior values and wishes as the starting point of a discussion that may result in an evolution, reinterpretation, or reaffirmation of those values.

Second, health-care professionals who work with patients with newly acquired disabilities have a very difficult challenge in balancing the duty to respect the patient's autonomy with their responsibility for the patient's well being. No simple formula regarding advance directives and the patient's wishes will allay this challenge because exactly what counts as the patient's autonomous wishes is precisely what is at point. This issue is probably not clarified for the clinician by theoretical constructs about "new persons." It is better conceived in terms of supporting patients and families through a crisis by assisting them in coming to genuinely appreciate their options.

Our review of the issues in informed consent in rehabilitation care has shown that within the rehabilitation context, informed consent is best conceived as a process, perhaps as a communal process involving significant others. Informed consent in rehabilitation care must be educational and ongoing. This represents a contrast with much of acute care in which informed consent can sometimes be conceived and implemented as an event that takes place in a single conversation before an intervention. Similarly, the role of

family in the consent process is clearly heightened due to the issues of personal identity raised by the onset of permanent disability.

The Social Model of Disability: The Social Construction of the Self and of Disability

The preceding section has suggested that rehabilitation and disability care cannot avoid confronting extremely profound questions of human existence. That is, simply trying to apply an ethical formula from acute care such as “the patient has a right to refuse treatment based on his or her values and wishes” is difficult due to the way traumatic injury can undermine the self and call into question the relevance of the patient’s previously held values. That is, the question becomes when has patient developed an ability to appreciate new options, possibilities and ways of life such that we can speak of the patient’s ‘fully informed consent’?

Furthermore, the **educational model** or process model of informed consent seems to highlight the fact that the self and his or her values can be fluid and change over time. The **self** is somewhat **socially constructed** in that family, other significant social systems, and the circumstances of one’s life help to shape its development. Similarly, **disability** is also a fluid concept that must be **socially interpreted**. *The history of rehabilitation care is a history of subverting the commonly held assumptions regarding disability.*

Rehabilitation care first undermined the assumption that disabled military veterans could not perform significant activities of daily living. However, rehabilitation care continued to embrace the assumptions of a **medical model of disability** for many years. Disability was assumed to be an intrinsic part of the impaired person and identical to being “**handicapped.**” The medical model conceives of disability and handicap as identical to **sickness**, something **to be cured** through treatment. We can see this kind of assumption reflected in the names of rehabilitation hospitals such as “curative” and in the logos of many institutions that show persons getting up

from wheelchairs or throwing away crutches. Disability is characterized as something to be overcome through treatment that leads to cure.

Rehabilitation care has contributed to the development of a **social model of disability**. On a social model, **disability** is a **complex interaction** between the **person** with an **impairment** and the **environment**. For instance, a person who does not see well has a physical impairment. If there are no supportive measures available such as corrective lenses or computers that can easily enlarge font size, then the person would seem to have a disability in terms of doing certain tasks such as reading small print. On this model, disability is not necessarily identical to a handicap but is simply an inability to do certain tasks.

The main premise of the social model of disability is that the translation of an impairment into a handicap is largely a function of the organization of social factors. Being unable to walk is not a handicap unless wheelchair users must face insurmountable barriers to transportation and access to public places such as job sites. On this interpretation of disability, physical and mental impairments are simply variations in the range of human existence, akin to height or weight. Society may often unwittingly design structures and institutions for an arbitrarily narrow range of humans such as when it makes airplane seats too narrow or close together for large people, places store shelves too high for smaller people, or makes doors to buildings too heavy to be used by elderly people or persons in wheelchairs.

The social model of disability does not see disability as something to be cured any more than one would try to eliminate tallness or shortness. The goal of rehabilitation care is to aid the patient in maximizing his or her potential to accomplish activities of daily living and **integration** into the **community**. The means to this end will often include teaching the patient to use assistive devices and current technologies. However, the problems faced by persons with disabilities can only be addressed in a limited fashion within the clinic. The social attitudes and environmental structures necessary to facilitate **community integration** require **advocacy** and **political action** in

order to be brought about. As a result, the **ethical principles** of **rehabilitation** become more about **human rights** and **social justice** than about beneficence.

Ramifications of the Social Model of Disability for the Reconstruction of the Self

We have made thematic that the problem of informed consent in the rehabilitation setting is largely a problem relating to the “application” of the patient’s values to the treatment choices to be made. In the acute care setting, such an application can be relatively unproblematic. However, the life-changing nature of an acquired disability can challenge the person adapt and evolve his or values and attitudes if he or she is to fully appreciate his or her options.

Of course, the **social** and the **medical models** may suggest different approaches to viewing **disability**. *On the simplest level, the **medical model** suggests an attitude of “overcoming” disability through **treatment and cure**; the **social model** through **reorientation of values and activism**.*

Most simply, the dominant way in the United States that one’s self-image is constructed is through one’s employment, his or her job. Almost immediately after being introduced to someone, we ask, “What do you do?” A medical model of disability might judge the success of rehabilitation in terms of a return to one’s former employment. Of course, medical care can fall short of achieving this goal and the process of finding new goals must be undertaken. Coming to accept that one’s former occupation may no longer be plausible can form a significant and difficult struggle. The social model of disability can call into question whether this identification with a particular occupation is an optimal way to view one’s self. Some persons undergo a fairly profound alteration of perspective due to injury and choose to change professions despite the recovery of all functioning necessary to return to their former employment. In other words, the self is reconstructed in such a way that formerly self-defining tasks are no longer seen as important.

Many have suggested that in order to truly appreciate the possibilities of his or her life, a patient must come to accept not only his or her particular impairment, but also come to see him or herself as a **member** of the **“disability community.”** There are two very important reasons why this might be beneficial. First, because disability can make one “different,” becoming a member of the disability can mitigate the destructive effects of social and psychological isolation and separation. Second, and more important from the perspective of the social model of disability, identification with the disability community can lead to understanding that many of the problems the person with an impairment will encounter are as much a function of society as of the impairment.

Coming to identify oneself as a person with a specific type of impairment provides a certain degree of mastery of the situation. For instance, once one sees oneself as belonging to a group of persons with a specific disability, one can procure information from support groups or other organizations independently of medical professionals. Being a member of this group of persons with a particular disability allows for a certain predictability in that one’s own situation is likely to follow established patterns that others have gone endured and for which coping techniques may be available. In its simplest terms, one can avail themselves of the experiences of others.

Similarly, viewing the experience of others and identifying with that experience may facilitate seeing disability according to the social model. That is, one can come to see that many of the **limitations** that accompany **disability** are **socially contrived** due to the **arbitrary construction of public spaces**, the **uninformed attitudes** of employers and citizens, and the **failure** to provide extremely beneficial **support services**. These realizations can lead to identifying with persons with disabilities as part of a **minority group** against which **society discriminates**. As a result, the ultimate outcome of fully appreciating one’s possibilities for life with a disability may be identification with an activist mentality in an effort to transform the social circumstances that “handicap” persons with disabilities.

Case Illustrations: Reconstructing the Self according to Medical and Social Models of Disability

Our discussion of informed consent to this point would seem to strongly recommend the social model of disability. It would seem to be common sense that accepting one's post-traumatic condition is the most fundamental aspect of seeing the possibilities in one's future. Furthermore, identifying which limitations are arbitrarily imposed by society can be liberating. That is, one does not mistakenly see oneself as intrinsically limited and damaged in ways that are actually socially constructed. Such benefits are illustrated by the well publicized story of Larry McAfee. However, we would be remiss if we did not note that there are occasional striking examples of those who seem to derive strength precisely from an abject failure to accept their situation. Clearly, the most noted example of this attitude is the actor Christopher Reeve.

The story of Larry McAfee is that of a young man who became quadriplegic following a motorcycle accident in 1985. McAfee was an engineer prior to his accident which caused him to be placed in a nursing home. Unable to bear the monotony and indignities of confinement within a nursing home, McAfee sought to end his existence by a shutting off of the mechanical ventilator that helps him to breathe. In 1989, McAfee's right to refuse treatment was affirmed by the Georgia courts. Because no one wished to execute this right on McAfee's behalf, he used his engineering skills to design a switch that would enable him to turn off the ventilator himself. However, he never used this switch.

During the period in which he was seeking the right to refuse treatment, Larry McAfee came into contact with members of the Independent Living Movement. This movement was begun by persons with disabilities who sought to help persons with disabilities to remain within the community and to have access to the range of opportunities to which most members of society have access. McAfee came to see the possibilities within community

living arrangements. Using a sip-and-puff wheelchair and computer technology, Larry McAfee was able to achieve an increasingly self-directed life that includes using his engineering skills.

McAfee's story was dramatized in a made-for-TV movie called *The Switch*, starring actors Gary Cole (as Larry McAfee) and Craig T. Nelson (as a local radio personality who became friends with him). The movie illustrated the theme that a seeming application of one's informed consent rights to refuse treatment can actually be a result of artificially narrow options being presented. McAfee's metamorphosis was one of moving from a position in which he saw his problem as mainly medical and intrinsically a part of him, to a position in which he saw the problem as a political one in which the State of Georgia arbitrarily chose to provide resources to isolate persons in nursing homes rather than support services that would foster opportunity for persons with disabilities. Acceptance of one's impairment is accomplished by understanding its meaning within a social context. Meaningful existence is not contingent on medicine's ability to eliminate the impairment. The late actor Christopher Reeve represents a polar opposition to this view.

In his best selling autobiography *Still Me*, Christopher Reeve demonstrates a defiant attitude toward his disability. He consistently seems to derive the strength to go on by insisting that he will be "cured" of his injury by breakthroughs made by medical researchers. In fact, he refers to acceptance of an inability to walk as having "given up." He proudly displayed this attitude and his particular form of activism was mainly directed to campaigning for more research on ways to "cure" spinal cord injury. While most disability activists seek more funds for appropriate "care" of persons with disabilities and alterations of public spaces to accommodate all persons including those with disabilities, Reeve argued for a greater channeling of funds to cure.

Reeve is clearly a controversial figure in the disability community. His strength seems to draw not from accepting a new identity but refusing to accept the loss of his prior identity, i.e., from seeing himself as "still me," as

the autobiography declares. He constantly insisted that he would one day reclaim this identity through a cure. Although the passage of time seemed slightly moderated the extreme nature of his views, in general, he remained focused on his identity as an able-bodied person to the end of his life.

Let's Get Radical: Understanding Informed Consent as Oppression of Difference

If you had an opportunity to peruse some of the websites noted at the beginning of the lecture, you've seen that the history of bioethics is stood on its head by many of these organizations. In general, they begin with the story of Larry McAfee in mind. That is, they argue that few people ever want to decline treatment. Many people decline treatment because they simply do not have sufficient resources to obtain the social support they need to live happy and productive lives. Like McAfee's apparent choices, "choices" to forgo life-sustaining treatment after traumatic injury are not choices at all but expressions of the despair and isolation that society has artificially contrived by the way it narrowly organizes access to places of work, education, and recreation.

This kind of thinking follows from a social model of disability. On such an interpretation, the goal is to redesign society so as to accommodate a greater range of variation among human capabilities. On an architectural level, the concept of "universal design" has prospered. This concept seeks to make living space accessible to virtually all persons. For instance, it is possible to make showers such that one does not have to lift his or her leg, or even get out of one's wheelchair. Why not always design them so? In this sense, an impairment that prevents one from lifting his or leg very high is no different from being of short stature. It is simply another place on the range of human variation. To build a society that makes it difficult for such variants to get into showers or to reach shelves in the grocery store is simply exclusionary.

Some disability activists believe that bioethicists are colluding in the "killing" of persons with disabilities by our emphasis on "choices" that are not really choices. Furthermore, many ethicists endorse "futility" policies that

allow physicians to make unilateral choices to enter DNR orders over objections of patients and families. (Recall our discussion of futility in Week 7 of the Clinical Bioethics course). Disability activists see this as a way of devaluing their lives and calling them not worth living.

The Disability Perspective on the History of Bioethics

(1) Birth

- Baby Doe Cases – In the 1970s and very early 1980's, a number of cases came to public attention known as the "Baby Doe" cases. In these cases, a child born with Down's syndrome required surgery to correct a life-threatening problem. In some of the cases, the surgery was relatively minor but needed in order to remove obstructions to allow nutrition & digestion. As one looks at commentaries by bioethicists (They were called "philosophers" and "theologians" back then) and testimony of physicians in the records of the court transcripts, the burdens of Down's syndrome to the patient and the family were unfairly described as unbearable. In sum, disability advocates make a strong case that these cases were about being unwilling to tolerate the lives of persons with a disorder such as Down's syndrome.

(2) Death and Dying

- a. Bouvia & McAfee – Social support issues not given sufficient attention.
Along with the case of Larry McAfee, disability activists point to that of Elizabeth Bouvia, a 25-year-old woman, whose legs were paralyzed from cerebral palsy. In 1983, in California, she began a campaign to be allowed to refuse food while remaining in a hospital till she died. This case took many twists and turns. Eventually, Elizabeth gave up this quest. But, subsequent accounts have started to criticize the role of prominent ethicists who focused on Elizabeth's rights while ignoring the social factors (loss of job & boy friend) that may have contributed to depression and feelings of worthlessness.
- b. Nancy Cruzan (Missouri, 1990) – Is PVS a disability? Are we depriving the disabled of life when we remove the artificial nutrition & hydration from a person in persistent vegetative state? (The Schiavo case in Florida follows this same pattern of reasoning.)

c. Robert Wendland (California, 2002) – This is a case of a patient with a severe cognitive impairment from a motor vehicle accident. Just how impaired he was depends on whom you ask. But, he was at best, quasi-cognizant and required a feeding tube to remain alive. His wife eventually (after a number of years) asked for removal of the tube. The patient's mother objected and a court battle ensued. In the end, the CA Supreme Court sided with Wendland's mother.

In the death and dying cases, you can see that there can be a case that the language of choice opens the door to withholding treatment that might be delivered if we did not perceive the person as having a disability. But, the question quickly becomes, when does the underlying condition support the idea that the treatment is disproportionate to the effects it will bring about?

That is, should we think about a person in PVS as simply having a cognitive impairment the same way we think about a person with Down's syndrome having one? And what about those persons in quasi-cognitive states in between unconsciousness and consciousness?

- (3) Pre-natal testing – The article by Raines in the Matt Weinberg collection points out that pre-natal testing essentially can identify a number of genetically linked diseases in utero. Unfortunately, there is no treatment for these conditions. In essence, termination of the pregnancy is the “treatment” for a positive test result. Is this, in effect, genetic discrimination against persons with disabilities?